Women's Views of their Lives After Infertility Treatment Fails

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Research Problem

Approximately one in six couples of childbearing age in the United States suffers from infertility. Only about 50% of the couples who are medically treated are eventually able to give birth to a child. Treatment can last anywhere from a few weeks to many years, even when there is little chance of a positive outcome. Couples tend to find it extremely difficult to end unsuccessful infertility treatment (Taylor, 1990; Black et al., 1992). While both men and women are adversely affected by their experience with infertility, this study limits its focus to women.

Clinical literature suggests that the inability to bear children creates a major developmental crisis for women who want to become mothers (Rogoff-Thompson & Thompson, 1990). Infertility usually disrupts a woman's sense of identity, her important relationships, and the structures of meaning which she developed early in life (Becker, 1990). The failure of infertility treatment is likely to extend this crisis in time, especially if a woman chooses not to become a mother through adoption.

Research, theoretical, and clinical literature provide only limited help to the clinician who is trying to develop a better understanding of the needs of an infertile woman who is making the transition to a life without parenthood. Empirical studies, both quantitative and qualitative, have primarily examined the stress and coping of women and couples who are *currently* in medical treatment. Only one study examines in depth the adaptation of women who have *ended* their medical treatment for infertility (Morley, 1994).

Research Question

How do women view their lives after ending fertility treatment which has not resulted in the birth of a child, if they have not chosen other means of becoming a parent?

Methodology

Data Collection: Participants for this qualitative study were located through a mailing sent to local members of a national organization for the infertile. Three in-depth interviews were conducted with a sample of ten infertile women who had stopped

treatment at least six months earlier. A semi-structured interview guide was utilized. All interviews were audiotaped, and later transcribed verbatim. Tapes were reviewed between interviews. This process allowed the researcher to identify themes to pursue, evaluate what data was missing, and plan for the next interview. It also helped in the identification and management of bias. Field notes logged aspects of the interviews which were not captured on tape, and also served as a journal in which personal feelings and reactions were logged and processed immediately after each interview. This activity was intended to make the researcher as aware as possible of her own emotions and values, thus helping in the management of bias.

Data Analysis: The dissertation describes the analytic process in considerable detail, especially the development of themes and categories. Data were analyzed according to the procedures of grounded theory (Glazer & Strauss, 1967; Strauss & Corbin, 1990; Glazer, 1992). Using the constant comparative method, comparisons were made between instances of the same categories in the data from all respondents, revealing the properties of these categories. There were two major phases of data analysis. The first phase involved the identification and initial exploration of categories built from the interview data. This phase of analysis identified categories, but did not suggest the relationship between these categories. The second phase placed the data on a time continuum, enabling the examination of key processes and bringing the interrelationship of the categories to life by revealing how these categories flowed and interacted over time.

Theoretical notes were written throughout the research process to track the researcher's ongoing thinking about the data. Procedural notes documented the research process, and various types of documents and tables were created to reduce the data for analysis.

Results

In recalling their infertility treatment, respondents highlighted its physical, emotional, and relationship impact on their lives. They emphasized that medical professionals tended to maintain hope even when treatment was failing, offered little help with the decision to stop treatment, and distanced themselves when such a decision had been made.

In terms of their current experience, nine respondents were still hoping for pregnancy. Most said that marriages and other relationships had been stressed by infertility. Respondents emphasized the importance of support and communication, especially with husbands. Those who were out of treatment for less than a year experienced intense and painful affect, especially sadness over the "loss of a dream." They felt angry about their situation and about the impersonal care received during infertility

treatment. They were afraid of an unknown future and old age without children. Energy focused on managing affect, and on dealing with a loss of identity and a sense of inadequacy. Pregnant women and young children were avoided.

Respondents out of treatment over a year and a half described affect as more manageable. They were attempting to redefine their identities, and were focusing on marriage, friendships, and activities. These women were also concerned about having "nurturing outlets," especially relationships with children. They said that infertility had changed them, mostly in positive ways. Some said they were moving on with their lives. They felt happy, no longer thought about infertility every day, pursued interests with pleasure, and enjoyed spending time with friends and their friends' children. Others described having more difficulty. They still experienced painful affect, spoke *more* about hoping for pregnancy than women out of treatment under a year, and continued to avoid pregnant women and children.

The study suggests that the evolution of hope is a key process in respondents' lives after they stop treatment, and that it has three phases: (1) hope of pregnancy; (2) acceptance of the likelihood that there will not be pregnancy; and (3) *new* hopes. Forty "markers" of moving on are identified, as well as ten risk factors associated with more difficulty moving on.

Implications for Social Work Practice

The findings of the study have a variety of implications for social work practice. The first concerns assessment and clinical intervention. Whether or not a client mentions infertility, it is incumbent upon the clinician to ask whether her childlessness is voluntary or involuntary. Infertility may be a key factor in her current difficulties. A narrative approach to assessment is most appropriate with infertile women. Clients need to be allowed to begin their story at whatever point in time feels most relevant to them. Such a narrative assessment can be supplemented with more structured exploration of a number of key areas, including the risk factors identified by this study.

A clear understanding of the client's motivations for motherhood and of *what* she has lost can help the clinician assess whether her current experience is dominated by grief and personal loss (loss of a baby), fear and uncertainty about the future (loss of identity), or a sense of guilt and failure (inability to meet expectations of others). The assessment of what has been lost bears implications for the choice of treatment modality.

The study has numerous other implications for clinical intervention. Since most respondents manifested strong feelings about the actual process of medical treatment only after stopping, one major implication is that the post-treatment period is an important time to make services available. Another implication relates to the finding that respondents'

recovery was eased and facilitated when they could freely communicate their grief to their husbands. This finding suggests that marital intervention is frequently a treatment of choice. In light of the finding that physicians seldom helped respondents to consider stopping treatment, another implication is that social workers should educate medical professionals about the needs of women whose treatment is failing, and about what happens to women who end unsuccessful infertility treatment without adopting. Understanding how women view their lives after stopping unsuccessful infertility treatment has the potential to help social workers prepare physicians and patients to assess how much treatment and what sort of treatment options make sense for a particular couple.

The study's implications for social policy are numerous. As stated above, it was indicated that both physicians and patients find it difficult to discuss or set limits on the extent or duration of infertility treatment. When limits are not discussed, doctors and patients sometimes extend treatment, despite very poor odds of success, in a shared experience of "false hope." Various factors contribute to this situation, including the frequent reluctance of physicians to acknowledge treatment failure. Extended treatment has already been challenged by managed care companies, which have begun to set limits to infertility treatment. As evidenced by the wider health care debate, such limits can be reasonable or unreasonable. Limits in the area of infertility treatment should be developed with the participation of infertile people, based on a full understanding of their psychosocial needs. There should also be a more just distribution of medical resources; currently less than half of all infertile Americans enter infertility treatment, largely because of its high cost.

The study supports the idea that carefully designed qualitative studies can be of use to practicing clinicians in areas where human experience is understood in a limited way, and where intervention is therefore particularly challenging. There are also ample data to confirm that participating in this qualitative study was of value to respondents. Most were eager to tell their stories, and reported that the process of doing so was helpful to them in a number of ways.

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